

# Developing an Individualized Treatment Plan for CFS



*Chronic illnesses provide challenges for health care professionals and patients alike. CFS can be an especially difficult chronic illness to manage. Here, Dr. Alan Pocinki offers some clinical tips for integrating CFS patients into a primary care practice.*

**By Marcia Harmon, Director of Communications**

**C**an health care professionals really deal effectively with chronic fatigue syndrome (CFS) in a primary care setting?

According to Alan Pocinki, MD, the answer is yes. Dr. Pocinki treats CFS patients in his internal medicine practice in Washington, D.C. In fact, about 10 percent of his practice is now comprised of CFS and fibromyalgia patients.

“The treatment of CFS is primarily symptom-based and involves both pharmacological and nonpharmacological therapies,” says Dr. Pocinki. “It doesn’t require a CFS specialist to diagnose and manage this illness.”

That’s good news because there are very few clinicians in

the United States who specialize in the treatment of CFS, and most patients can’t travel hundreds of miles to see them.

According to Dr. Pocinki, there are three elements to successfully incorporating CFS patients into your practice and helping them manage their illness. “The first is simply the willingness to learn about CFS. Managing CFS can be done in a primary care setting by physicians, nurse practitioners and physician assistants who are willing to learn about the illness and to work closely with patients.”

The other key elements are addressing the frustrations of managing CFS up front and then working with the patient in a team approach to develop

an individualized treatment program.

## **Rampant frustrations**

Dealing with chronic fatigue syndrome can be a frustrating process for both patients and their health care professionals. Acknowledging this can be a key step in managing this illness effectively, says Dr. Pocinki.

Sometimes patients carry “scars” that can damage their relationship with medical professionals. When patients have to see numerous doctors before getting a diagnosis, or face skepticism from their medical providers or family, they can unwittingly carry that frustration and anger into every encounter at the doctor’s office,

earning them a reputation for being angry, difficult patients.

And medical professionals who have faced too many of these so-called difficult patients can dread seeing them come through the door.

“Patients can become very frustrated with the illness and what it does to their lives and their health, and they can be very hurt by dismissive attitudes from people who don’t believe CFS is a real illness, or who think it’s real, but it’s a form of depression. They bring that frustration into the doctor’s office with them, and it can interfere with effective therapy,” says Dr. Pocinki.

“Physicians can be equally frustrated by their lack of knowledge about the complexity of this illness, the trial-and-error nature of most treatment, and seeing formerly productive people barely able to manage activities of daily living and not being able to offer much to help them.”

Sometimes just having a brief doctor-patient conversation that acknowledges these feelings on both sides can clear the air and encourage a problem-solving, team approach to the management of CFS. It can also help set realistic expectations for both parties. CFS is a chronic illness, and treatment usually takes place over a period of years, not months. There is no quick fix.

### Individualized treatment plan

Dr. Pocinki believes the other key to an effective doctor-patient relationship is developing an individualized treatment plan for each patient. While this is important for many illnesses, he believes it’s absolutely essential for CFS because of complex physiological factors and psychological factors that impact treatment.

“There is considerable variability from patient to patient in what symptoms are present, in the severity of those symptoms and in the efficacy of specific treatments,” says Dr. Pocinki. “What works for one CFS patient may not necessarily work for another. This is true of both drug and nondrug therapies.”

Patients and their health care team also need to pay attention to the psychological factors that impact treatment. “People respond differently to life’s challenges,” says Dr. Pocinki. “Someone who rises to meet a challenge will respond differently to getting a chronic illness than someone who is easily overwhelmed. Someone who has a family support system may cope much better with the career and lifestyle changes imposed by CFS than someone without that support. Someone who has no health insurance or disability coverage may experience a lot more anxiety and stress than someone without those financial worries. These are all important factors for the doctor-patient team to acknowledge because they can either mitigate or exacerbate symptoms depending on individual circumstances.”

Personality and psychological factors also play a role in an especially critical area of CFS management—postexertional malaise—the

worsening of symptoms after physical or mental exertion that almost all CFS patients experience. “Patients need to recognize and tell their health care team whether they’re someone

who can stay within their energy budget, or they’re a push-crash type of person who will always overdo on days when they’re feeling better and cause their symptoms to flare up.”

This would be an area where occupational therapy, counseling or cognitive behavior therapy (CBT) might be useful. “Patients who learn to recognize—and then change—activity, behavior or coping patterns that trigger a worsening of symptoms or a relapse will do better in the long run,” says Dr. Pocinki.

### Holistic Approach

In a managed care setting, with limited time available for each patient visit, it can be hard for medical providers to resist the temptation to deal with one symptom per visit. “But because symptoms of CFS are so interrelated, I have found that a holistic approach to symptom treatment works best,” Dr. Pocinki relates. “For instance, treating sleep problems in isolation may not be the best

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approach. I often tell patients that there's no way they'll ever feel better if they can't get a restful night's sleep. But they won't sleep better until their pain and depression are treated. So while sleep may be the first priority, I think pain, sleep and depression need to be treated concurrently."

It's also important to remember that a treatment that improves one symptom may worsen another. "For patients who are complaining of fatigue or cognitive dysfunction, stimulants like Provigil, Ritalin or Adderall may be prescribed to boost energy and improve focus and concentration. And occasionally, for patients with orthostatic problems, stimulants like Sudafed or phentermine can increase blood pressure and heart rate and improve orthostasis. However, you can't prescribe stimulants without keeping a careful eye on how they impact other aspects of the illness. They can make rest and sleep more difficult, or worse, they can precipitate the dreaded push-crash cycle. Consequently, I've found that stimulants are an effective treatment for only about 10 percent of my patients."

Treating symptoms in a holistic way makes particular sense for CFS patients when it comes to pharmacologic therapies. Because patients are highly sensitive to medications, and dosages frequently have to be reduced to a fraction of the normal dose, it makes sense to limit medications whenever possible by prescribing drugs that treat more than one symptom. "For instance, Cymbalta, which can be prescribed for patients experiencing depression, also has pretty impressive pain-relieving properties, especially for neuropathic pain. The nice thing about Cymbalta is that it doesn't take a high dose to benefit patients. Many antidepressants not only improve mood, but also help with pain and sleep."

Another example is Lyrica, which can be used to treat both pain and sleep problems. "A lot of my patients find Lyrica incredibly helpful when pain interferes with sleep."

### Careful Evaluation

In addition to determining the unique physiological and psychological factors for each patient, Dr. Pocinki carefully evaluates each symptom to develop a treatment plan.

"In CFS patients there is such a heterogeneity of types of pain, types of sleep disorders, types of fatigue, that for each symptom, the health care provider really needs to talk to the patient and explore the nature of the symptom," advises Dr. Pocinki. For instance, there are numerous kinds of sleep problems seen with CFS. Some patients have disrupted or fragmented sleep. Others have hypersomnia, sleeping 12 to 14 hours a day, but waking exhausted. Still others have primary sleep disorders like sleep apnea and restless legs syndrome.

"It's important to explore the nature of the sleep disturbance with each patient because different sleep problems are treated with different therapies," says Dr. Pocinki. "For instance, Ambien, Lunesta and Sonata help many patients fall asleep, but may not be adequate if sleep maintenance is an issue. And drugs like Klonopin, lorazepam and diazepam have anti-anxiety, anti-movement and muscle relaxant properties that are helpful to some patients, but not to others."

Dr. Pocinki recommends a sleep study if sleep issues persist. "Just one night in a sleep lab can really help guide treatment," he says. "I've seen patients with sleep apnea who don't know they have it. Since sleep apnea has significant metabolic effects and makes weight loss very difficult, this can be a factor if the treatment plan includes weight-loss strategies to help reduce fatigue and joint pain. And because muscle relaxants can make sleep apnea worse, they may not be a good choice for some CFS patients who have this sleep disorder."

Sleep apnea is an exclusionary condition for a CFS diagnosis under the current diagnostic criteria unless treatment doesn't resolve the CFS symptoms. "Unfortunately, that's often the case," says Dr. Pocinki. "Once the sleep apnea is treated, they still have CFS and their symptoms persist. Treating sleep apnea may not be enough by itself to make a noticeable difference in overall sleep quality, but it's nonetheless an essential part of a comprehensive sleep treatment program, since without addressing apnea other sleep therapies are unlikely to be effective."

Exploring a symptom like pain requires equally careful evaluation because CFS patients

experience so many types of pain, including muscle, joint, visceral and neuropathic pain, as well as headaches. “I can think of five different kinds of headaches CFS patients seem predisposed to,” says Dr. Pocinki. “There are migraines, sinus, muscle/joint, dehydration and sleep-deprivation headaches, and the treatment varies for each.”

Through long experience with CFS patients, Dr. Pocinki has learned the importance of carefully evaluating each patient’s pain—and not underestimating that pain. “Patients have often experienced pain for so long that they no longer realize how much pain they’re in and how much it’s contributing to their illness. I often hear ‘It’s not that bad,’ or ‘I’ve learned to live with it.’ Instead of exhibiting drug-seeking behavior, the typical CFS patient insists on only taking pain medication if absolutely necessary. But with chronic fatigue syndrome and fibromyalgia, this is the wrong approach. Even if daily medication only reduces their pain 10 to 20 percent, this can have a significant effect on their energy, mood, sleep and overall well-being.”

Dr. Pocinki also believes that evaluation helps guide effective drug and nondrug choices for each patient. “It’s amazing how many patients can be helped with nondrug therapies when they are evaluated carefully. For instance, for a patient who keeps reinjuring muscles or joints, the most effective nondrug therapy is teaching the patient how to minimize the risk of reinjury, and how important it is to avoid activities and exercise that exacerbate the pain. And heat, toning exercises, graded exercise and acupuncture—and salt, fluids and compression hose for patients who have orthostatic instability—can help reduce pain too. Prescription medications are usually required as well, but I always start with the basics.”

### Long-term Prognosis

Not enough research has been conducted on the long-term course of the illness to accurately define recovery rates and prognosis for chronic fatigue syndrome. Some studies suggest full recovery is rare, but Dr. Pocinki believes this shouldn’t hinder medical professionals from taking on more CFS patients.

## ADDITIONAL RESOURCES



Dr. Alan Pocinki sees a clear link between chronic fatigue syndrome, autonomic dysfunction and joint hypermobility in many of his CFS patients. To download his article on this topic, just go to [www.cfids.org/bonus/hypermobility.pdf](http://www.cfids.org/bonus/hypermobility.pdf)



The Science & Research of CFS, a special issue of the *CFIDS Chronicle*, carries an in-depth article on “Clinical Care for CFS” that many health care professionals may find especially useful. Dr. Pocinki is one of seven clinicians who provided specific, practical information to guide clinicians in supportive and symptomatic treatment for CFS. See [www.cfids.org/special/treatment.pdf](http://www.cfids.org/special/treatment.pdf)

“Statistics from my own practice indicate that this patient population *can* be helped. About 15 percent of my CFS patients are fully recovered, 35 percent are partially recovered, 40 percent are improving and only 10 percent have been disabled for years with few signs of improvement. There’s no quick fix, but with supportive care and symptomatic treatment, there is hope. Helping patients improve function and become more independent with activities of daily living makes a huge difference in their quality of life.

“Seeing a 17-year-old who was so debilitated she could barely stand graduate from college five years later—with an A average—is the kind of thrill that keeps primary care doctors like me going to work every day.” ■

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